

LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON SOCIAL DEVELOPMENT

Monday 26 August 1991

The committee met at 0859 in the Delta Hotel, Ottawa.

REGULATED HEALTH PROFESSIONS ACT, 1991,
AND COMPANION LEGISLATION

LOI DE 1991 SUR LES PROFESSIONS
DE LA SANTÉ RÉGLEMENTÉES
ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 43, the Regulated Health Professions Act, 1991, and its companion legislation, Bills 44-64.

Reprise de l'étude du projet de loi 43, Loi sur les professions de la santé réglementées et les projets de loi, 44 à 64, qui l'accompagnent.

ALLERGY AND ENVIRONMENTAL HEALTH
ASSOCIATION, OTTAWA BRANCH

The Chair: The standing committee on social development is now in session. I would like to welcome everyone this morning. I call as our first presenter, the Allergy and Environmental Health Association. You have 20 minutes for your presentation. We would ask if you will leave a few minutes at the end in case any of the committee members have any questions. Please begin your presentation now.

Mr Brown: Thanks very much, Madam Chairman, and thanks very much to the committee for this opportunity to talk to you. I am speaking on behalf of the Ottawa branch of the Allergy and Environmental Health Association. This is the largest branch of our association in the province—we have about 300 members—and we are also the largest per capita branch of the association.

People with environmental sensitivities are people who react to substances in the environment at levels of exposure that do not affect most other people. George Thomson, who is now Deputy Minister of Labour, who I am sure is familiar to all of you, did a report in 1985. In his report he listed symptoms involving every system of the body, with effects ranging from mild discomfort to serious disability. For some people, environmental sensitivity is an annoyance. For the more seriously affected people, it is a disabling problem.

We have achieved some progress, thanks to some of you, and thanks to people in human rights commissions and so on. The most recent thing that I would like to inform you about is a letter from Marion Boyd, Minister of Education. She writes that her ministry now agrees that environmental sensitivity should be considered as a possible contributing factor in learning disabilities and behaviour problems in schools, so school boards should take this into account when applying the Education Act, and meeting children's special needs.

Environmental sensitivity is not an illness. It is a phenomenon of reacting to substances, as I have described, which can be caused by a wide variety of illnesses. Some of them are well understood. Others are not well enough understood for medical intervention. The only method of

treatment that people know of is avoidance of sensitive substances. The problem is not new. I mention a couple of these things because there is a lot of mythology in the media about this problem, and in some other circles.

Environmental sensitivities have been experienced for generations. They are not new to the medical community either. Medical literature goes back for a couple of centuries. The Department of National Health and Welfare published a bibliography a couple of years ago with hundreds of articles dating back decades. The information is not hard to find. Within an hour of being diagnosed in 1979, I was reading a book on the subject in a library. The book was published in 1951, so this is not a new problem, and it is not new to medicine.

Just a bit of background about our association. We are the largest of five self-help groups in Ontario. Our main activities include self-help, helping people deal with life-style changes required for dealing with this problem, dealing with employers, dealing with various authorities, and helping people, for instance, with human rights concerns related to having this disability. Most of our activities in the Ottawa branch relate to helping people deal with adverse differential treatment by Community and Social Services, Ministry of Health, and authorities outside the provincial purview.

There are a number of attachments. I mentioned the letter from Marion Boyd. There is also the last page of a letter from Darlene Koski, president of our association—which had a different name in 1984—talking about suicides of people caught in this adverse differential treatment in the health community. There is a letter from the coroner relating to a suicide of a person who was told by the Ministry of Community and Social Services that his problem was all in the mind; a letter from Catherine Frazee indicating her willingness to help the Ministry of Health deal with some of the attitude problems on this illness; a statement of the federal human rights commissioner talking about some of the abuse that people with this problem experience.

Most of the concerns in the Ottawa branch relate to adverse differential treatment. This relates quite closely to this legislation, because it is something that I think consumers should have recourse about. A lot of these problems have stemmed from the fact that over a period of time various authorities said that persons with this problem did not have a legitimate medical problem—that their symptoms were all in their mind, that these people were so crazy they were making themselves sick, and so on. In other words, statements were made which had a negative effect on the people's reputation for soundness of mind, their credibility as professionals, their expression of special needs within the community with landlords, employers, and so on.

This statement was made on the expressed reason of not understanding the physiology involved. I would suggest,

and I think you would agree, that it is inappropriate to make statements which reflect poorly on people's credibility, and on their reputation, when those statements are based on an absence of information. In order to make statements that hurt people, one requires evidentiary reason, due process and opportunity to respond. Such statements should not be made on the basis of an absence of information, or on the basis of people having a particular disability.

This is what happened, and there were a number of consequences which I would like to mention, and then discuss how this relates to the legislation that is proposed. The first of the consequences—and these consequences go from the least important to the most important for the three that I will list—relates to the actual damages that were caused to people by the fact that this statement was made. The insult was more damaging than the injury that it was added to. Families broke up. Professional reputations were ruined. People were told that they were not worthy of being treated by doctors who ignored their concerns. A number of people were killed. As I mentioned earlier, there have been a number of suicides of people who became frustrated with the health-care system, with the way officialdom was dealing with them, and with the fact that small things they needed, which were manageable, became impossible to deal with because of the attitude pollution around.

As bad as the first problem is, the second consequence is worse. We are a community of people who have been abused in the way that I have just described. Many of our people have had their careers ruined. And many people involved in this issue have friends who have either been caused disability unnecessarily or who have, in some of the extreme cases, committed suicide.

Material evidence relating to this concern has been brought to the authorities for some time. There has been some action towards research. There has been some action in Community and Social Services recently, and in Housing. But the abuse in the health care system has not been addressed. As a result, the people with this problem, the people coming forward, are coming forward with a very heavy emotional load, usually with a victim mentality. Our community is very fractured as a result of the tension which results from this kind of treatment. At the one end, we have people whose rage is not understood by others. At the other, we have people who may be financially independent who are trying to appease the bullies.

Between these two factions, and with a lot of other tension in our community, the second consequence I want to mention is that we have a problem as a community bringing forward a coherent statement of our concern, with an integrated representation. There are about five self-help groups in the province and, to be frank, there is a lot of tension. I think that sometimes the authorities have been confused by receiving conflicting messages from the various parts of our community.

The third consequence is worse. It is that the very authorities now in a position to help us—this includes some of the professionals covered by this act, some parts of the Ministry of Health, and some other parts of provincial government—are the authorities that have participated in or tolerated or

been compliant with the abuse. For these authorities to act now in a forthright manner, to speak the truth about the abuse, to act on the concerns that people have, would be an implicit, in some cases an explicit, acknowledgement that what has been done to this group is unethical. It is not just that it caused damage, but that it is unethical.

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I want to emphasize, underline and put in bold letters, that our organization is not bringing forward the issue of compensation. We are not looking for a witchhunt. We are simply trying to identify the political logjam that is preventing a constructive resolution of concerns on this issue.

If I could be permitted one quick aside, I will come back to relating what I have just said to the legislation. There is a strong likelihood that many psychiatric patients have undiagnosed sensitivities as the cause of their problem. Thomson relates a list of central nervous system symptoms which are listed here. Perrin Beatty, when he was Health minister, wrote us acknowledging support for the United States study which won a World Health Organization award, which strongly recommends checking for environmental sensitivities before embarking on potentially detrimental psychiatric interventions. The authors of this study, done for the New Jersey state department of health, are Ashford and Miller, a doctor of jurisprudence from the Massachusetts Institute of Technology and an immunologist for the University of Texas.

The focus in the Ministry of Health has been on conducting more research. I would suggest that when you have this kind of recommendation, and when the practice of screening psychiatric patients for sensitivities is not in place, you have a very, very strong likelihood, a virtual certainty, that some percentage of psychiatric patients should not be psychiatric patients but should be treated for environmental sensitivities. We would say that this group of people is being abused by the health care system, including by the mental health facilities branch of the Ministry of Health. That is an aside just to emphasize the importance of forthright action on this concern, and the importance of getting people out of the frame of bobbing and weaving to avoid acknowledging previous abuse and to get on with dealing with this problem.

I mentioned that the focus has been on research. If you see somebody down the road from your house, a kid being beaten up repeatedly or some other form of abuse—it is very useful to encourage research, but I think the onus is on the authorities to stop the abuse. I do not think that the government has acted on that. I think the government has a debt, given the previous encouragement of this attitude by the Ministry of Health.

With respect to the legislation, when there is widespread abuse in a profession—for instance, when there is toleration in the medical profession of dismissing consumers' concerns as being all in the mind when people are dying because of this—there should be some means of appeal around that profession. It should not be necessary for the consumers to go to a college representing that profession's interests. Even if we acknowledge that there is an interest in the College of Physicians and Surgeons of Ontario to have good medicine in the province, it should

not be the case where people being abused by a profession have to go to a self-regulatory agency to make their case. There should be some formalized institutional process of being able to go directly to their representatives, in this case representatives in Queen's Park and probably in the Ministry of Health, to deal with ethical and human rights concerns, which surely should take precedence over medical treatment.

The other elements I have in the brief relate to the section about controlled acts, I think it is subsection 26(2), and paragraph 26(2)13 relates to allergy testing. It was a little confusing to us why there was what seemed to be arbitrary specificity here, a level of specificity in regulating allergy tests and singling them out for regulation. That is a question there may be a good answer to, but there are a couple of concerns, if it is there, that I think you might want to address.

One of them is that there are many different kinds of sensitivity besides allergy, and if you are going to single out allergy you might want to single out all kinds of sensitivity, including allergy and non-immunological types of sensitivity. Reactions to toxicological sensitivity and food intolerance, for instance, which are not allergies, strictly speaking, might be covered in the legislation. The other element of that sentence relates to the fact that the type of act that is being controlled is where the positive indicator is a reaction of an allergic type.

So two points again: One, what if the positive indication is a reaction of a non-allergic type, which is life-threatening? In other words, if you are going to protect some of the members of the Allergy and Environmental Health Association of Ontario, the ones who have allergies, why not protect all of them, the ones who have other kinds of sensitivities? The second part of that is the idea that quite often the positive result of a test is not a reaction. For instance, in serial dilution titration testing recommended by Thomson in 1985, the positive reaction of the test is a neutralization of symptoms. However, a positive reaction can be caused on the route to finding a neutralizing shot or sublingual dose. So if you are going to protect people with allergy, why not protect a broader group of people with sensitivities? If you are going to protect people from tests where the reaction is an allergic reaction, why not protect them from tests where there are toxicity reactions? If you are going to protect people from tests where the reaction is positive, where a positive indication is a reaction, why not protect them from tests where a positive indication is other than a reaction, but a reaction may be caused during the course of the test?

I think that is all I need to put in a summary. Thank you.

Mr Grandmaitre: In your brief you are saying that environmental sensitivity is not a medical illness, but sensitivities can be caused by a number of illnesses. You were diagnosed in 1979. Tell me about your life before 1979. Were you struck with some kind of illness?

Mr Brown: I would rather avoid a description of my personal situation. I had this problem all my life. I went to a variety of specialists over a long period of time to find out what the problem was. Finally in 1979 I was fortunate enough to come across some British work on this subject and to find a doctor familiar with it and to be diagnosed. I

had medical problems before 1979, but I want to emphasize that the difficulty people have is more with the stigma attached, with the fact that they have been trashed on the basis of an absence of information. That is where the difficulty lies. In terms of this legislation, the concern is to try to give people an option for appeal other than going to the parties who are aligned with those who are carrying out the abuse.

The Chair: I want to thank you very much for your presentation this morning. The committee has received your written brief, and I would inform you and anyone else who is listening this morning that if there is additional information you think would be helpful to the committee during its deliberations, please submit further briefs and information in writing through our clerk. Thank you for appearing this morning.

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